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ABSTRACT

The effects of childhood epilepsy on family interactional patterns were examined with eight families with a child with epilepsy and eight matched control Ss. Families were observed in their home environment using a coded, direct observation tool, the Family Observation Record Keyboard System (FORKS), and the portable electroencephalographic telemetry system which allowed trained observers to code all social and nonsocial behavior of all family members together with clinical and subclinical seizures. Families with an epileptic child were found to behave differently than do families with a nonepileptic child: the behavior of experimental families was less stable across observations. Significant correlations were obtained between seizure activity and the behavior of the identified child. (CL)

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THE NATURALISTIC OBSERVATION OF CHILDHOOD EPILEPSY AND FAMILY SOCIAL INTERACTION

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Introduction

Frequently, clinical assessment instruments, including parental ratings, structured personality inventories, and child self-report scales are employed to obtain information regarding the adaptation of epileptic children to their natural environment. However, these indirect assessment tools do not generate the classes of data deemed necessary for scientists who are concerned with discovering the social relationship among family members, evaluating the effectiveness of various aspects of biomedical treatment, and developing functional models of behavior. In addition, these indirect assessment devices tend to focus on attitudinal dimensions of the respondent(s) behaviors rather than on specific behaviors that comprise the primary focus of most biomedical intervention. Published studies (Honig, Tannenbaum, & Caldwell, 1968; Radke-Yarrow, 1963; Sears, 1965) all show weak relationships between indirect assessment reports and direct observations of the same behaviors in the home milieu.

In order to avoid many of the problems inherent in traditional clinical assessment instruments, behavioral scientists are turning to coded direct observation systems (Antonovsky, 1959; Blurton-Jones, 1972; Patterson, Ray, Shaw, Cobb, 1969; Wahler, House, & Stambaugh, 1967). Direct observational techniques involve the coding of complex behavior under free response conditions occurring in the everyday environment of the individual under study with few or no constraints imposed by the investigator (Sackett, 1978). This paper presents some preliminary findings from such an instrument and its application to the study of epilepsy and family patterns of behavior.

Instrumentation

Edgefield Lodge, a mental health facility for children and families in Oregon, has developed a direct family observation instrument that meets psychometric and statistical standards regarding reliability, concurrent and construct validity, and generalizability (Grove, Goocher, Wilcox, Andrews, 1979). This instrument, the Family Observation Record (FOR) has been converted into a totally electronic encoding system, The Family Observation Record Keyboard System (FORKS), that permits

the integration of behavioral and electroencephalographic (EEG) data. In the present research, the FORKS is used to collect behavioral interactional data on all family members and concurrent EEG data from the child with epilepsy in the home environment setting.

The behavioral events are recorded on a keyboard (Figure 1) using five major

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Insert Figure 1 about here

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behavioral categories. One category, Social Norms, represents household rules of conduct as defined by the parents prior to each observation. The observer records whether a family member meets the household rules (SN) or violates them (VSN). The remaining four categories are defined by the observation system. These categories include (a) Social Interaction: Any verbal or non-verbal appropriate social interaction (ASI) or inappropriate social interaction (ISI) directed toward someone. Any appropriate social interaction in which a new conversation is begun or a topic of conversation is changed is defined as an Initiation. (b) Command Behavior: A mand is a command request or question which requires compliance. Responses to mands are compliance, non-compliance, successive approximation, and Do-For. (c) Consequence by Intent: Behavior in which the intent by the person emitting this behavior is to maintain, increase, or decrease another person's behavior which preceded it. Consequences may be positive or negative. (d) Seizure Behavior: Clinically observable seizures.

Procedure

Subjects. Eight families with a child between the ages of 7 and 13 (Mean age = 9.7) and with a seizure disorder participated in the study. These families were matched with eight contrast families with a child between the ages of 7 and 13 (Mean age = 9.4). All children received a neurological exam, including a complete EEG, and a psychological exam. In order to participate in the study, the children with epilepsy met the following criteria: An unambiguous history of clinical seizures; documentation of seizure types using free ranging video-telemetry; anticonvulsive levels within the therapeutic range; diagnosed as experiencing generalized or partial complex seizures; and free of other psychomotor impairments. The neurological and psychological examinations substantiated that the contrast children did not have any neurological impairments. All children were of normal intelligence as measured by the Wechsler Intelligence Scale for Children-Revised (WISC-R). Families in both groups included natural mother and father and from two to

four children. In addition, all family members had no other chronic or emotional illnesses and were free of substance abuse. All parents completed the Minnesota Multiphasic Personality Inventory and the Eyberg Child Behavior Inventory.

Method. Each family in both groups was observed on 4 separate occasions at monthly intervals. In order to insure comparability between observations, specific conditions were maintained during each observation. These conditions increased the probability that interaction would occur among family members, e.g., the observation included the evening mealtime, and family members were asked to remain in the major communal living areas of the home during the observation.

During a behavioral observation, the observer focused in rotation on each family member as the subject on eight separate occasions. Each family member is observed for a minimum of 24 minutes. The observer records on the keyboard which is connected to an eight-channel FM tape recorder via hard wires so that all behavioral information along with a time demarcation is stored on site. Concurrent with the storage of the behavioral data eight channels of EEG data are collected on a FM tape recorder. Following the completion of the observation, the tape is then decoded by a PDP-11 computer, edited by a neurologist and project staff, and stored for later analysis (Figures 2 and 3).

Insert Figures 2 and 3 about here

Results

Data are reported from 4 observations on each of eight epileptic and eight matched contrast families.

Stability and Interobserver Agreement. In order to examine the number of observations needed to attain stability, Fisher's Z-statistic for proportions was computed between the last observation and the average of the preceding observations on five behavioral categories of the family summary data and on six behavioral categories of the identified child's data. Stability was attained by the fourth observation ($Z < 2.57$, $p=.01$) in all categories examined for seven of the contrast families, but for only three of the eight epileptic families. Stability was attained by the fourth observation in four of the five behavioral categories for the remaining families. Similarly, the behavior of the identified child was stable by the fourth observation for seven of the contrast children but only four of the epileptic children. Again, behavioral stability was attained by the fourth observation in five out of the six behavioral categories for the remaining children.

Interobserver agreement between two observers was calculated using Kappa (Cohen, 1960). Satisfactory interobserver agreement was reached for the entire observation ($\bar{K}$=.78-.93). Interobserver agreement was also calculated for each of the ten individual behavioral categories using Light's extension of Kappa (Light, 1971). Interobserver agreement ranged from .78 to 1.00.

Comparison of Epileptic and Contrast Families. Two x 5 analyses of variance with repeated measures on the second factor were performed to investigate the differences between epileptic families and contrast families. The two factors in these analyses were Family Type (Epilepsy vs Contrast) and Observations, the repeated factor. The behavioral categories chosen for analysis were those that reliably discriminate "Normal" families from those who have a child with behavioral problems (Grove, Goocher, Wilcox, and Andrews, 1978). There were no significant differences between the rate of behavior emitted or received by the identified child and the child's parents. However, mean differences, although non-significant were in the expected direction. The children in the epileptic sample tended to behave more like children who have behavior problems. For example, the epileptic children emitted more ISI's (.084/minute) than did the children in the contrast group (.037/minute)($F=3.13$; $df=1,14$) and the epileptic children had more non-compliance (.121/minute vs .052/minute)($F=3.70$; $df=1,14$).

Seizure Activity. Analyses of Variance with repeated measures on the second factor were performed comparing the rate of seizures and average duration of seizures for the period one half hour before the observation, during the observation, and one half hour following the observation. Although there was no differences in the rate of seizures during these periods, there was a difference in the average duration of seizures. The duration of seizures was higher during the observation than before or after the observation ($F=3.57$; $df=2.48$; $p<.05$).

Pearson product moment correlations were performed between the rate and average duration of sub-clinical seizures during the observation and rate of behavior of the identified child during the observation. Average duration of seizures correlated with Responses emitted by the identified child ($r=.54$, $p<.01$). Rate of seizures correlated with Initiations received ($r=.63$, $p<.01$) and Responses emitted by the identified child ($r=.61$, $p<.01$).

Discussion

The Family Observation Keyboard System was subjected to a number of psychometric tests. Satisfactory stability and interobserver agreement were obtained. Results from four observations indicate that families with an epileptic child behave dif-

ferently than do families with a non-epileptic child. The behavior of families with an epileptic child is not as stable across observations as that of the contrast families. It is hypothesized that the unpredictable manifestations of the child's seizures account for this finding. For example, in one of the epileptic families for which stability was not obtained, the epileptic child had had a tonic-clonic seizure the day before two of the observations. Behavior of the family during these two observations was similar, but differed very significantly from the behavior of the family during the other two observations. This relationship between seizure activity and stability of behavior is being further investigated.

The preliminary findings do not show remarkable differences in the interactional patterns of epileptic and non-epileptic families in the behavioral categories assessed. However, the means from the epileptic sample were in the direction of the means obtained from a behaviorally deviant sample (Grove, et at; 1978). It is important to note that the epileptic sample in the present study may not be representative of the general epileptic population. The criteria for inclusion in the study precluded any family with social and/or cognitive disorders. In addition all families contained both natural parents. This exclusion may account for the findings that are contrary to those reported by other investigators (Aird and Woodbury, 1974; Henderson, 1953; Green and Harglage, 1971; and Kaye, 1951).

Significant correlations were obtained between seizure activity and the behavior of identified child. Three significant correlations were reported which accounted for more than 25% of the variance. In examining this relationship between seizure activity and the rate of initiations received and responses emitted by the epileptic child, it is postulated that family members compensate for the lack of the epileptic child's interaction by increasing the number of initiations during increased seizure activity. Subsequently, the epileptic child increases the rate of responding. To determine if there are any predictive relations between the behavior and epileptiform activity, conditional probabilities are being computed between the behavior immediately preceding and following a seizure, and the occurrence of the seizure.

Obviously, much more work remains to be done, but the methodology to investigate the behavioral impact of childhood epilepsy on family behaviors has been developed. The Family Observation Record Keyboard System with the portable EEG telemetry system makes possible the independent recording of clinical and subclinical seizures simultaneously with recordings of behavioral data. With further development of the methodological model, other behavioral, social, and medical concerns about childhood epilepsy can be investigated.

Acknowledgements

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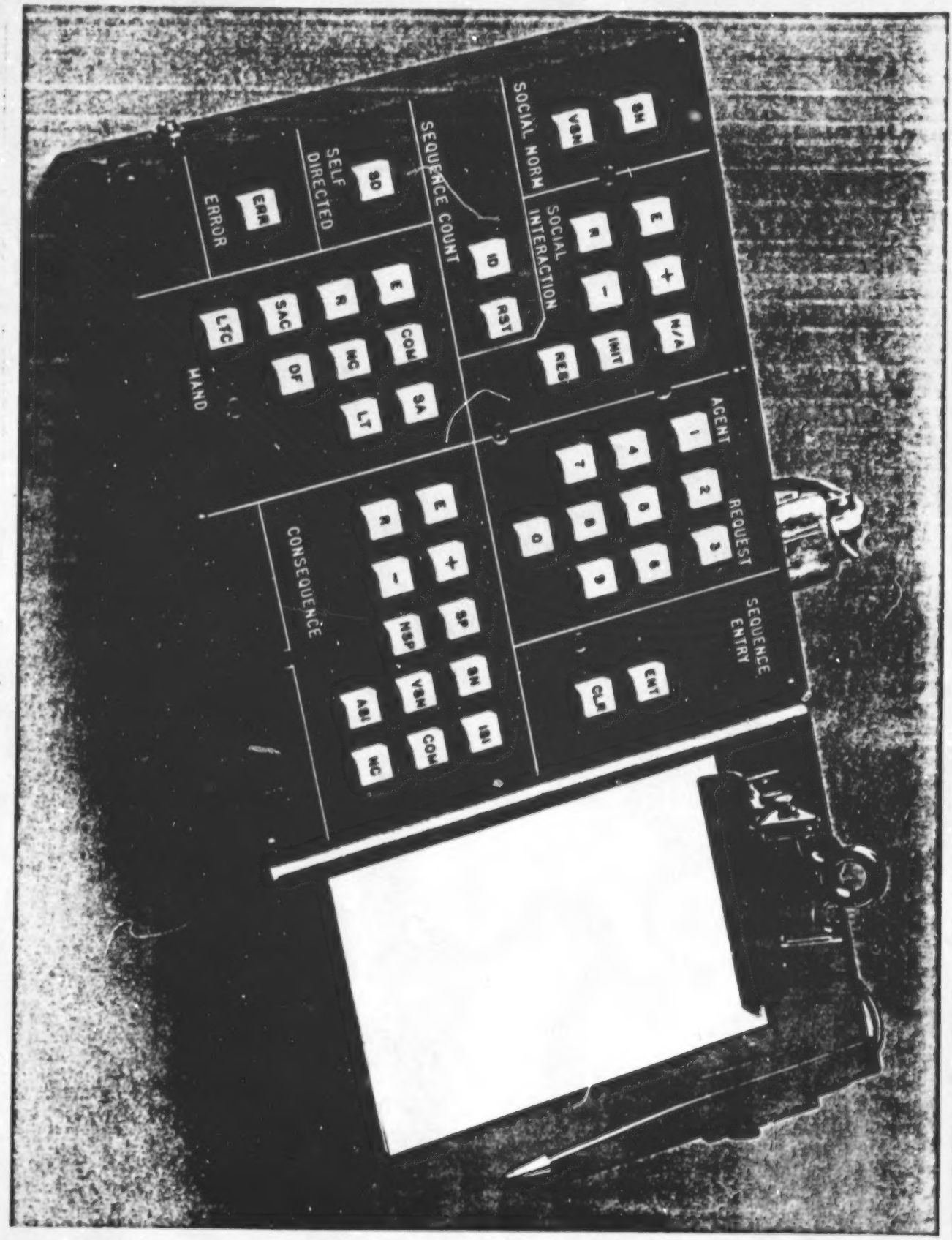
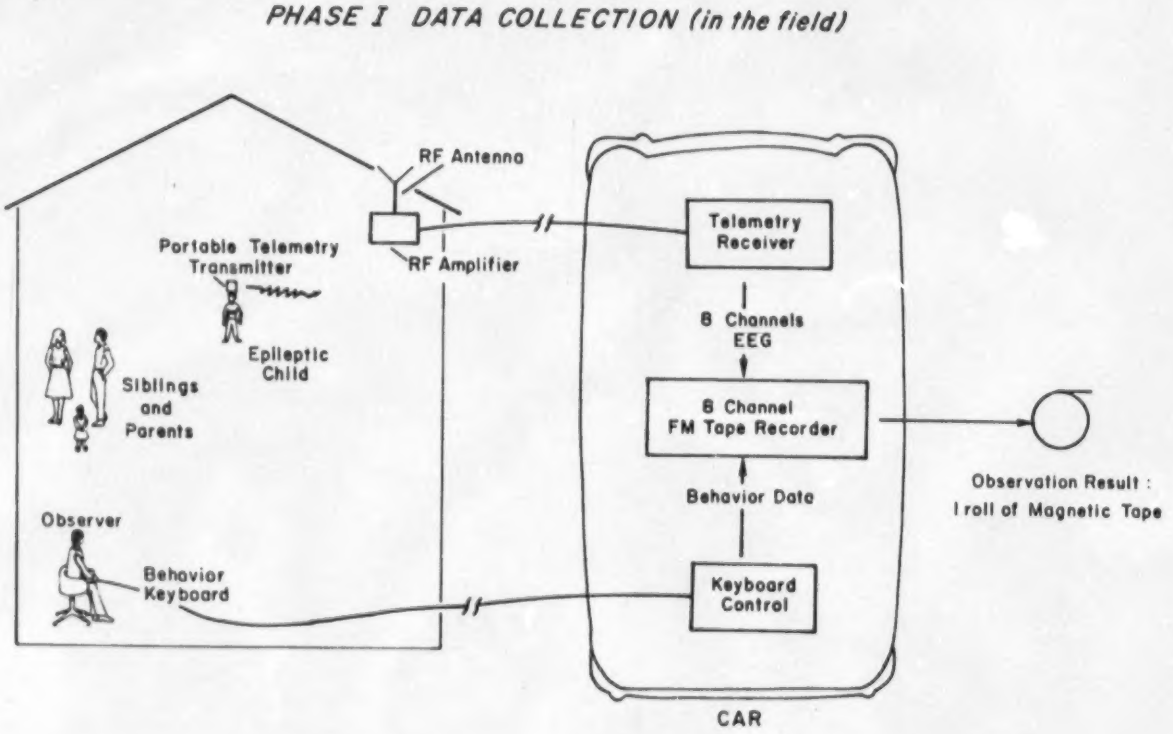


Figure 1. Family Observation Record Keyboard.



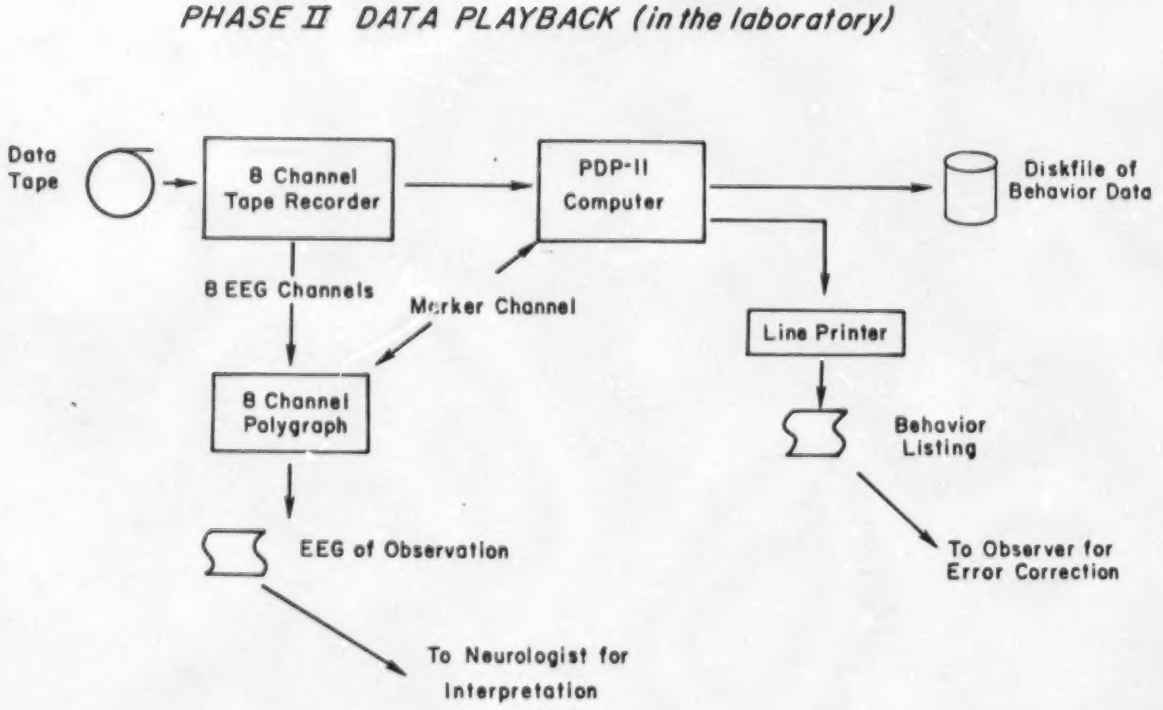
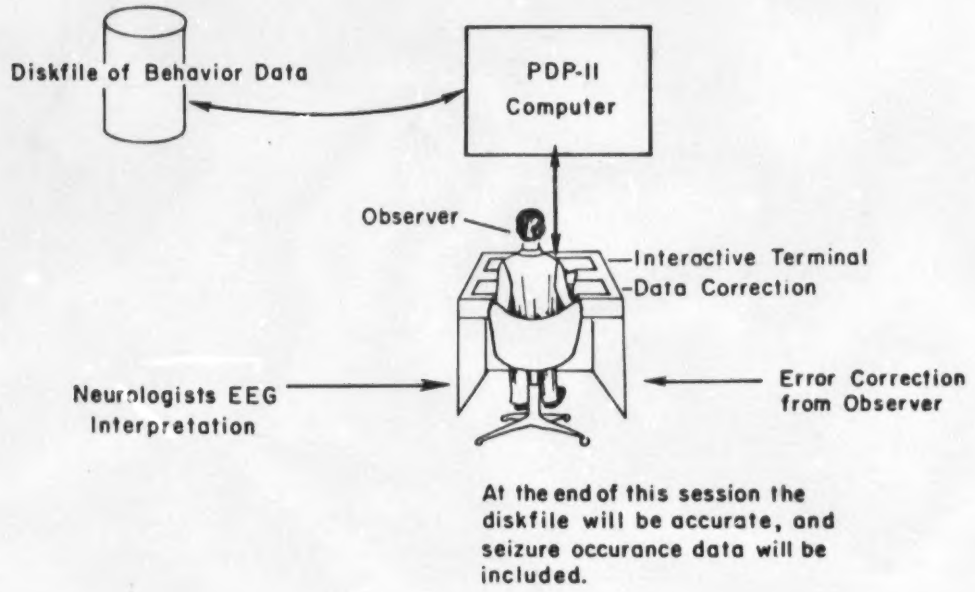


Figure 2. Family Observation Keyboard System: Phase I and II.

PHASE III ERROR CORRECTION and SEIZURE INCLUSION



PHASE IV DATA TRANSMISSION

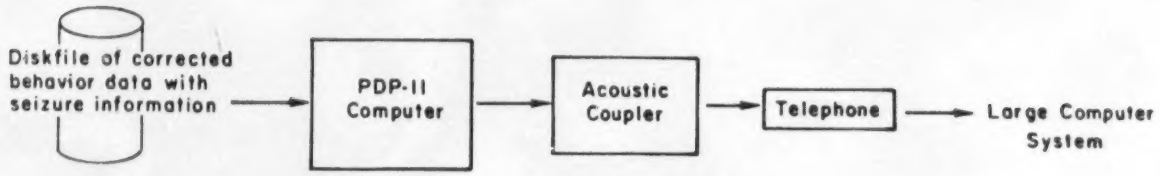


Figure 3. Family Observation Keyboard System: Phase III and IV.